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# CANCER FACTS

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National Cancer Institute • National Institutes of Health

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## Questions and Answers About Followup Care

It is natural for anyone who has completed cancer treatment to be concerned about what the future holds. Many patients are concerned about the way they look and feel, and about whether the cancer will recur (come back). Patients wonder what they can do to keep the cancer from coming back. They also want to know how often to see the doctor for followup appointments, and what tests should be done. Understanding what to expect after cancer treatment can help patients and their loved ones plan for followup care, make lifestyle changes, and make decisions about quality of life and finances.

### 1. What does followup care involve, and why is it important?

Followup care involves receiving regular medical checkups that include an evaluation of a patient's medical history and a physical exam. Imaging procedures (methods of producing pictures of areas inside the body); endoscopy (the use of a thin, lighted tube to examine organs inside the body); or lab tests may be a part of followup care for certain cancers. Physical therapy, occupational or vocational therapy, pain management, support groups, or home care may also be included in the followup care plan.

Followup care is important because it helps to identify changes in health. The main purpose of followup care is to check for the return of cancer in the primary site (recurrence), or the spread of cancer to another part of the body (metastasis). Followup care can also help to identify the development of another type of cancer, unknown or unusual treatment side effects, and late effects of cancer treatments (side effects that develop years after treatment).

It is important to note that cancer recurrence is not always detected during the followup visits. Many cases of recurrence are suspected or found by patients themselves between scheduled checkups. It is important for patients to be aware of changes in their health, and report any problems to their doctor. The doctor can determine whether the problems



are related to the cancer, the treatment the patient received, or an unrelated health problem.

## **2. How are followup care schedules planned?**

Ongoing health needs of patients differ. Followup care is individualized based on the type of cancer, the type of treatment received, and the patient's general health.

In many cases, it is not clear that followup tests improve survival or quality of life. This is why it is important that the doctor help determine what followup care plan is appropriate. The doctor may not perform any tests if the patient appears to be in good physical condition, and does not have any symptoms. It is also important for patients to talk with their doctor if they have any questions or concerns about their followup care schedule.

When planning a followup care schedule, patients should consider who will provide the followup care and other medical care. Patients should think about selecting a doctor with whom they feel comfortable. This may be the same doctor who provided the patient's cancer treatment. For other medical care, people can continue to see a family doctor or medical specialist as needed.

Some patients might not have a choice in who provides their followup care. Some insurance plans pay for followup care only with certain doctors, and for a set number of visits. Patients may want to check their medical coverage plan to see what restrictions, if any, apply to their followup care.

In general, people who have been treated for cancer return to the doctor every 3 to 4 months during the first 2 to 3 years after treatment, and once or twice a year after that for followup appointments. At these followup appointments, the doctor may recommend tests to detect other types of cancer such as a mammogram to detect breast cancer.

## **3. Do some doctors or clinics specialize in followup care?**

Very few comprehensive cancer centers and academic medical centers have clinics devoted to the followup care of adult cancer patients. However, there are a number of clinics that provide followup care for pediatric cancer survivors. Patients can contact local comprehensive cancer centers or academic medical centers to see if followup care clinics exist in their area. A list of National Cancer Institute (NCI)-designated cancer centers is available in the fact sheet *The National Cancer Institute Cancer Centers Program*. It can be found at [http://cis.nci.nih.gov/fact/1\\_2.htm](http://cis.nci.nih.gov/fact/1_2.htm) on the Internet. The Association of Cancer Online Resources (ACOR), a cancer information system that offers access to electronic mailing lists and Web sites, provides a list of long-term followup care clinics for children and adolescents treated for cancer.

This list can be accessed in ACOR's Pediatric Oncology Resource Center at <http://www.acor.org/ped-onc/treatment/surclinics.html> on the Internet.

#### **4. What questions should people ask their doctor about followup care?**

Important questions to ask a doctor about followup care include:

- How often should I see the doctor for a routine visit?
- What followup tests, if any, should be done?
- How often should these tests be done?
- What symptoms should I watch for?
- If I develop any of these symptoms, whom should I call?

Many patients find it helpful to write these questions down and take notes, or tape these sessions with their doctor to refer to at a later time.

#### **5. How can patients deal with their emotions effectively during followup care?**

After cancer treatment, it is common for a person to experience emotions such as stress, depression, and anxiety. Many people find it best to talk their feelings out with family and friends, health professionals, other patients, and counselors such as clergy and psychotherapists. Being part of a support group may be another effective outlet for people to share their feelings. Relaxation techniques such as imagery and slow rhythmic breathing can also help in easing negative thoughts or feelings. Reaching out to others through participation in volunteer activities is also an effective way for a person who has completed cancer treatment to feel stronger and more in control. If these symptoms persist, however, patients should talk to their doctor about referral for further evaluation of what may be causing, or contributing to their distress.

#### **6. What kinds of medical records and information should patients keep?**

It is important for people undergoing followup care to keep records of their health history. A patient may not always see the same doctor, so having this information available to share with another doctor can be helpful. The following types of information are important for a patient to keep track of:

- Specific type of cancer (diagnosis)
- Date(s) of cancer diagnosis
- Details of all cancer treatment, including the places and dates where treatment was received (e.g., type and dates of all surgeries; names and doses of all drugs; sites and total amounts of radiation therapy, etc.)
- Contact information for all doctors and other health professionals involved in treatment and followup care.

- Complications that occurred after treatment.
- Information on supportive care received (e.g., pain or nausea medication, emotional support, nutritional supplements, etc.)

**7. What other services may be useful for a patient during followup care?**

Other services that may be helpful during followup care include financial aid and housing/lodging. To obtain more information about services after cancer treatment, a person can contact national cancer organizations, hospitals, the local church or synagogue, YMCA or YWCA, or local or county government agencies. To get the most from any of these services, it is important for people to think about what questions they want to ask before calling. Many people find it helpful to write out their questions, and keep a pad and pen at hand while they talk to someone. It is also important to learn how to apply for the service, as well as find out any eligibility requirements.

**8. Does the NCI have guidelines for followup care?**

No, the NCI does not have such guidelines. However, some organizations such as the American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network (NCCN) have these guidelines.

The ASCO is a nonprofit organization that supports clinical research. ASCO has published clinical practice guidelines on a variety of topics, including followup care for breast, colorectal, and lung cancer. These guidelines, called Patient Guides, are available on the ASCO Web site at [http://www.asco.org/people/rs/html/m\\_patguides.htm](http://www.asco.org/people/rs/html/m_patguides.htm) on the Internet.

The NCCN, which is also a nonprofit organization, is an alliance of cancer centers. The NCCN provides Patient Guidelines, which include followup care information for breast, colorectal, and prostate cancer. The Patient Guidelines are available on the NCCN's Web site at <http://www.nccn.org> on the Internet.

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**Sources of National Cancer Institute Information**

**Cancer Information Service**

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY (for deaf and hard of hearing callers): 1-800-332-8615

**NCI Online*****Internet***

Use <http://cancer.gov> to reach NCI's Web site.

***CancerMail Service***

To obtain a contents list, send e-mail to [cancermail@cips.nci.nih.gov](mailto:cancermail@cips.nci.nih.gov) with the word "help" in the body of the message.

**CancerFax® fax on demand service**

Dial 1-800-624-2511 or 301-402-5874 and follow the voice-prompt instructions.

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